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ABSTRACT

This booklet highlights some of the insights that five mothers of children with developmental disabilities have gained after a generation of working together to improve the lives of people with developmental disabilities in Wisconsin. It discusses civic activism, the critical importance of organized parent support, difficulties in collaborating with professionals, and social changes that affect the conditions for volunteer action. Lessons learned include: (1) parents with very different visions for their own sons and daughters can find common ground and work together for important changes; (2) victories can have unexpected consequences; (3) broader coalitions increase political clout, but once legislation is passed and appropriations are made, there will be many questions to settle about how the benefits are divided; (4) insiders in the system can and will be a help when common issues are discovered; (5) what took years to gain can be lost at the stroke of a pen; (6) ask for help and relinquish control when necessary in the interest of attaining what seems to be important; and (7) families need to be involved in finding solutions to problems, not only in identifying problems. (CR)

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ED 442 225

# *My house is covered with papers!*

## Reflections on a Generation of Active Citizenship

Connie Lyle O'Brien & John O'Brien

with

Fran Bicknell

Sue Kendrick

Mary Murphy

Peg Olsen

Jayn Wittenmyer

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Wisconsin Council on Developmental Disabilities

COMMUNITY SUPPORTED LIVING SERIES

EC 307861

# *My house is covered with papers!*

## Reflections on a Generation of Active Citizenship

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## Contents


Introduction ..... 5

Turning Points ..... 7

- Difficult choices ..... 7
- Understanding professional voices and claiming your own child ..... 8
- Choosing civic activism ..... 10

Essential lessons ..... 11

- The critical importance of organized parent support ..... 11
- Continuing difficulties in collaborating with professionals and assistants ..... 12
- Continuing uncertainties ..... 15
- An ethic of active citizenship ..... 19

Unfinished business and the troubling growth of a sense of "entitlement" ..... 21

- Unfinished business ..... 21
- Entitlement, a troubling new mood ..... 22
- The mood of acceptance ..... 24
- Living in the entitlement gap ..... 24

The path to active citizenship ..... 27

- Social changes affect the conditions for volunteer action ..... 27
- System changes challenge citizen control ..... 28

Lessons ..... 33

## Introduction

When he exclaims "My house is covered with paper!", Brad Bicknell echoes his mother, Fran. Throughout his 45 years, Brad's autism and blindness have led her into a life of active citizenship which has opened new paths for people with developmental disabilities and their families. Her activism has covered their house with papers concerning the creation of a local special education advisory committee, the founding and growth of the Wisconsin Autism Society, the passage of Wisconsin's special education law, the development and operation of the Portal Foster Center, the creation of Dane County's Chapter 51 Board and the growth of a comprehensive county service system. Today, when Brad comes home for weekend visits, he confronts papers on the proposed redesign of Wisconsin's medicaid funded system of long term support and Dane County's demonstration of self-determination.

Brad's is not the only Wisconsin household that has been covered with paper as his generation of people with developmental disabilities has grown up. This booklet highlights some of what five women, introduced below, have learned from a generation of working together to improve the life-chances of people with developmental disabilities in Wisconsin. Their lives intertwined and took positive shape in ways that would have never appeared if they had not given birth to a son or daughter with a developmental disability.

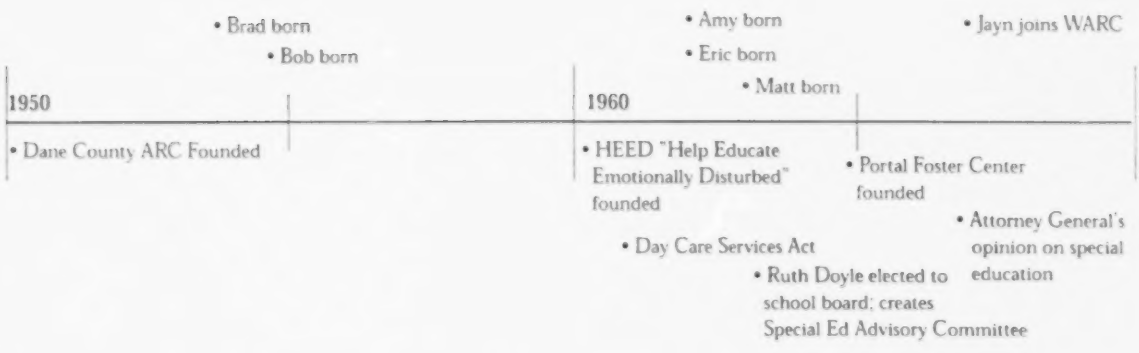
These children have grown into adulthood during a period of great change in their whole world and in the world of people with disabilities. They, and their mothers, pioneered early intervention, family support services, special education based on integration and preparation for real work, employment services, and community residential services. None of them has finished opening new territory for themselves and other people with disabilities. All of their mothers continue to make important contributions to the civic work of shaping policies and programs that offer people with developmental disabilities the opportunities and supports they need to be full and responsible citizens.

One of these contributions is to share some of what they have learned. The Wisconsin Council on Developmental Disabilities funded the process of producing this booklet. Marcie Brost conceived the idea and shaped each step of its development. She and Connie Lyle O'Brien interviewed each woman individually. She, Howard Mandeville, Connie Lyle O'Brien and John O'Brien spent a day listening to all five women reflecting as a group on their analysis of the current situation and their concerns for the future of the system they play a continuing role in shaping. Connie Lyle O'Brien and John O'Brien are primarily responsible for organizing this rendition of what these parent pioneers have to teach. Each of the points in the booklet is grounded directly in their words, which Connie and John taped, transcribed, visually recorded, and studied. Extended quotations from the transcripts appear in italic type.

These five women each have their own distinctive ways of contributing, their own unique gifts, and their own views. Each has her own constellation of personal supports and community memberships. Within their common commitment to increasing opportunities for people with developmental disabilities and their firm belief in the importance of civic activism, they have had many productive disagreements. They have had lively discussions about the specific policies and structures that should guide the development of the services their families' rely on. They have differing views of the role of congregate services and the possibilities for what some people call "natural support." This booklet focuses less on these important differences than on some of the commonalities that they recogize as they reflect on their lives.

All of us who have worked on this booklet hope that parents who are close to the beginning of their careers as civic activists will find encouragement and important lessons here. We hope that those who work professionally with people with developmental disabilities and their families will learn half as much from reading their perspective as we have from listening to these five people in person.

**Fran Bicknell** has always been interested in politics and democracy. She's been an active member of the League of Women Voters and her church's Social Action Committee where she began her work on fair housing. Fran majored in Social Studies and planned to work in a YWCA public affairs office. Brad, her fourth child and only son, was born prematurely resulting in his being blind. At age six Brad was diagnosed as having autism. Fran and her husband, Bill, soon discovered that there were no services or supports available to help them learn how to understand Brad's needs. Fran's life's work has been to use her political and organizing skills on behalf of her son and other people with disabilities. Brad lives with three other men in a group home, built with HUD funds that Fran and Bill secured as board members of a non-profit agency. He visits with his mother every other weekend. Fran says, "He has adjusted beyond my wildest dreams."


• Brad born
• Bob born
• Amy born
• Eric born
• Matt born
• Jayn joins WARC
1950
1960
• Dane County ARC Founded
• HEED "Help Educate Emotionally Disturbed" founded
• Portal Foster Center founded
• Attorney General's opinion on special education
• Day Care Services Act
• Ruth Doyle elected to school board; creates Special Ed Advisory Committee



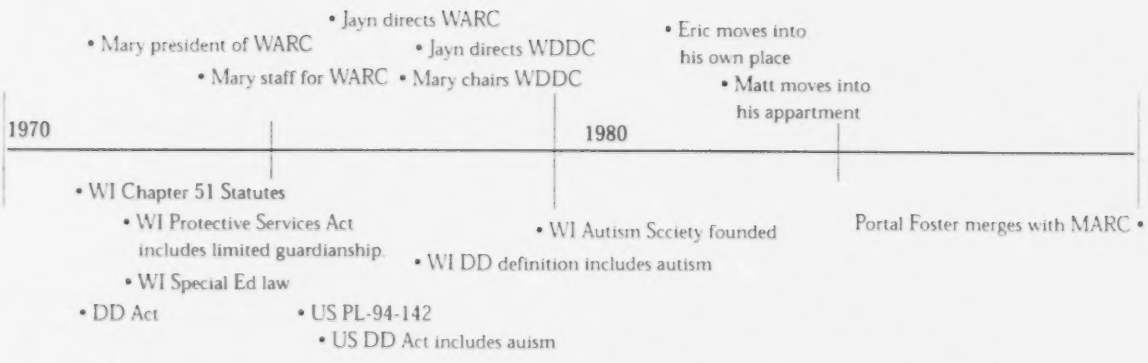
6

**Sue Kendrick** and her husband adopted three children. Their middle child, Matthew, has cerebral palsy. As

Matthew was growing up, Sue worked for United Cerebral Palsy advocating with parents around their children's education while simultaneously trying to find an appropriate school for Matthew. In 1977, UCP received a DD Council grant to figure out how to support people with physical disabilities. This work helped shape the COP program which designs supports around individual people. Matt graduated from school and was still living at home. Sue said, "I decided that since I was out there telling other people about supported living, I'd better get my own kid out of the house and into his own apartment. He moved into his own place in downtown Madison when he was 21. Matthew, who is now 36, bought his own condominium this year using money he inherited from his father.

**Mary Murphy**, a sportswear buyer before her three children were born, says she was privileged to raise her children

before going back to work. Mary says nothing in the way she grew up or was educated prepared her for the work she's done on behalf of her middle son, Bob, who was born with Down Syndrome. But in Mary's words, "I never stopped trying to learn, over the years taking university courses on relevant topics and attending and contributing to many national and state conferences that dealt with pertinent issues and information." Since 1962 she has been on numerous local and state committees and boards concerned with people who have disabilities. She was president of the State ARC in 1972. Bob, who was institutionalized at 7 months of age and returned home to live a few months later, now shares an apartment with another man with a disability and a paid support worker. Mary says, "Who would have thought that anyone who went through most of his life being labeled severely/profoundly retarded could be living in a supervised apartment? I could never have imagined it, but it's true!"

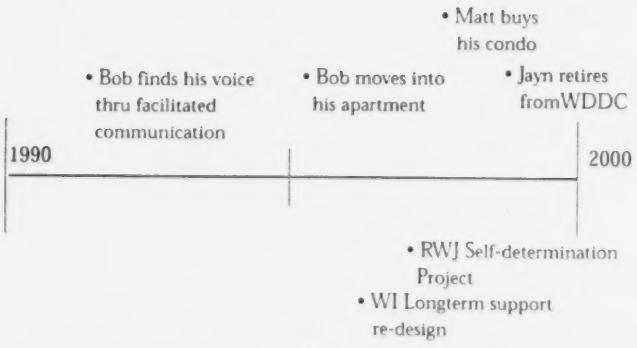

• Jayn directs WARC
• Mary president of WARC
• Jayn directs WDDC
• Eric moves into his own place
• Mary staff for WARC
• Mary chairs WDDC
• Matt moves into his appartment
1970
1980
• WI Chapter 51 Statutes
• WI Protective Services Act includes limited guardianship
• WI Special Ed law
• DD Act
• US PL-94-142
• US DD Act includes auism
• WI Autism Scciety founded
• WI DD definition includes autism
Portal Foster merges with MARC •



7

**Peg Olsen** describes herself as a civil rights activist who marched with Martin Luther King. Peg grew up in a housing project, raised by a single mother with very little money. Determined to get out of the projects, she became a nurse. She met and married Ward, a physician and the couple have three children. Their oldest, Eric, has Down Syndrome. Early in Eric's life the family lived in Boston, where Peg became active in ARC work, and she's never stopped. Peg and Ward always wanted the best for Eric, and continue to fight for him to maintain what he has achieved. As Peg describes her family's life, "Our family is a family. Our kids are very much involved in life and bettering it for other people. Two of our children are attorneys living in San Francisco, California and Portland, Oregon, and Eric has two jobs, he's living on his own with support, he's continuing to mature."

**Jayn Wittenmyer** and her husband, Bill, have three daughters. Their middle child, Amy, has Down Syndrome resulting in a severe heart condition. Jayn, who has spent her life working on behalf of Amy and other people with disabilities, retired as Director of the Wisconsin DD Council in 1997 where she served effectively and for longer than any other person in that position. Jayn retired early to be at home with Amy, who needs much more support because she has developed Alzheimer's disease and her heart condition has worsened. Amy enjoys her parents' constant presence and frequent visits from her sisters and their families. Jayn continues to learn the many lessons that Amy has to teach, and she is taking those lessons to politicians and parents in a continuing effort to improve the lives of people with disabilities and their families.


• Matt buys his condo
• Bob finds his voice thru facilitated communication
• Bob moves into his apartment
• Jayn retires fromWDDC
1990
2000
• RWJ Self-determination Project
• WI Longterm support re-design

## Turning Points

Even more intensively than other children, children with severe disabilities depend on their families to offer not only a safe home with a climate of love, positive expectations, and emotional caring but also to sustain the work of caring year after year. The work of caring includes providing physical assistance, implementing activities that promote health and development, discovering and coordinating and maintaining necessary resources, and protecting. Usually, mothers are responsible for the largest part of the work of caring. How that work is done, shared, and supported defines important conditions for a family's quality of life.

### Difficult choices

A generation ago, most mothers with a significantly disabled child faced three difficult choices:

1) Turn inward and do the work of caring for their child with some help from whatever special program might be locally available until their child dies or their ability to do the work of care breaks down and their child is institutionalized;
2) Follow prevailing professional advice and institutionalize their child; or,
3) Turn outward and join other parents in working to change social conditions for children with disabilities and their families while supporting one another in doing the work of caring.

The first choice defined disability as a private trouble, a family misfortune whose relief depends on charity when a family can't pay for treatment and placement. The private trouble understanding* reflected most people's beliefs about disability, which were justified by inhumanly low expectations about the potential of people with disabilities. The third choice clearly defines disability as a public issue, a situation that could face any family which merits a publicly guaranteed and funded response as a matter of promoting the common good. The public issue understanding challenged most people's beliefs about disability, adding disability to race and poverty as issues of civil rights to be promoted and protected. Some mothers who opted for institutionalization became active in working for social change on behalf of people with disabilities while others did not. Some mothers changed their minds about institutionalization, bringing their children home with a renewed sense of their rights.

| Everyday work of caring | Civic Action: No | Civic Action: Yes |
|---|---|---|
| Yes | *At home Private trouble* | *At home Public issue* |
| No | *Institution Private trouble* | *Institution Public issue* |

*At about the time that parents of people with developmental disabilities were making those changes, sociologist C. Wright Mills made the distinction between "private troubles" and "public issues" as a way to make sense of the social and political changes that defined the times. See *The sociological imagination. (1959)*. New York: Oxford.



9

## Understanding professional voices and claiming your own child

Families didn't face these choices as explicit options. They negotiated them as they made sense of an unexpected reality that called for some kind of shift in their expectations and reconfiguration of their family life.

*We had just begun our lives as a young married couple. Eric was our first child. We were married in June and he was born the following April. Especially when you're so young, you assume you're going to have these brilliant children because, of course, that's how your life is supposed to be, and you just make that assumption and then to just sort of have this dropped on you, sort of "Chung!" So we were immediately faced with how to reconfigure our idea of what family life was all about. To rethink how we were going to find success here with Eric. How is that going to be defined? You know, without ever saying it, to think of things that Eric did as milestones. (Peg)*

An early challenge facing each family was making sense of the voices of professionals who took responsibility for defining the meaning of disability. In their uncertainty, some met professionals with a frightening certainty about the meaning of their child's disability, the shape of the child's future, the child's negative effects on family life, and the best thing to do. Sometimes trusted family advisers and extended family members validated professional authority.

*When we went for Bob's four month check-up the doctor said, "I've decided that all of the things that you have been asking about add up to his being a Mongoloid." At least, he didn't tell me on the phone. The only knowledge I had of what this was came from an "Abnormal Psychology" class I had taken when I was a business major in undergraduate school.*

*The doctor's recommendation was to institutionalize him. He said it wouldn't be fair to our other son if we tried to raise him at home. He said, "You can't raise another child around him." We only had one other child at the time. Bob's my middle child. And, of course, I wasn't supposed to have another child, either.*

*He said Bob would learn very slowly, and that he would learn nothing at all after the age of twelve. He said he would probably develop "early senility" and that he might have severe respiratory difficulties and heart trouble. He told me that Southern Colony was a good institution that he had referred others to. He said he'd even been there himself.*

*We consulted with other people –clergy, who agreed with the doctor, and family members concurred. [Bob was placed in the institution three months later, at the age of seven months]*

*We didn't feel guilty because we did what the people we respected, who we consulted, told us was the thing to do. The only thing to do. And they certainly told us it was particularly important that we not submit our other son to those horrible things we would have to do to raise Bob in our family midst. We didn't feel guilty because we had done what we thought was right. But then we lived with it for a while, and we didn't like it one bit. Every time we went down to that institution, I'd come home with a migraine headache. (Mary)*

Others heard a different message. Sometimes a professional prepared the way for a mother to find her own voice by encouraging hope and confidence in the mother and raising a question mark over the potential advice of other professionals. This question mark opens up the room a mother needs to find her own sense of who her child is and what matters.

*...my obstetrician was not negative. One of the very first things he said to me when he came into my room was, "Don't let them make you forget that you are a mother first." (Peg)*

Sometimes another family member's response to the child gives the gift of a life-clarifying moment.

*... so my mother arrives at the hospital [with] this layette set and this crib thing. Ward is reading Aristotle. He actually is. Ward is home reading Aristotle, trying to make sense of the world. And I'm trying to think, "Geez, how am I going to get this kid home?" And my mother comes in with this stuff, and I think, "Hey, she's just happy as a clam." And I say, "Mom. You do understand that this is a genetic problem. That this ain't going to get better?" And she looked at me like, "So what?" ... "No, no", she says. "He'll do just fine. We'll all just help you, and this will all be just fine." (Peg)*

Sometimes an extended period of professional uncertainty gave a mother and her family time to develop their own perspective, against which they could test professional advice.

*Unlike the others, we were not told to institutionalize Brad when he was a baby. It wasn't an obvious problem like Down Syndrome. Actually, they told us he would have to be raised as a blind child, they didn't even say he was blind. This was a period when they didn't even tell parents what was going wrong with their children. So we knew he was blind, but we didn't know what else. He had fifty words at age two and then he just quit talking and he didn't talk again until he was six. Those were the mystery years. He wasn't actually diagnosed with autism until he was six. Then we took him to the Boston School for Blind Babies to be evaluated when he was ten. We took him for a ten day evaluation, and I stayed with him. They did let the parents stay. That was one good thing. That was when we were told to put him in an institution – that we would never be able to handle him when he was a teenager. Our girls were all with us. Sherry was a sophomore in college by then, Betsy had just graduated from high school, and Tani was in tenth grade. They weren't having any of that, "Brad's not going to any institution." Of course, we felt that way too, but we were glad they did. The evaluation cost more than we could afford. I don't remember the amount, but it seemed like a lot, and we didn't follow their advice. So after ten days, all we got was "Give him up, there is nothing you can do. He's just going to be impossible to manage when he gets big." (Fran)*

Sometimes hard experience led to a new understanding and a turnaround.

*Bob had been down at Southern Center for about seven months, which [the experts said] was the only way to go. "Anybody who tries to keep a child at home, has rocks in their head." They called us from the institution one night to say they were going to take him over to the University Hospital because he was bleeding rectally. And I said, "You're not going to take him. We will take him." It turned out his intestines collapsed into one another, and it turned out they were able just to operate on him. They did an appendectomy trusting that the scar tissue would support the weak spot in his intestines and it did. We brought him home, and he's been home ever since. So that's how we made the turn-around. But we would have anyway, I'm sure. We brought him home for convalescence. You don't have a 15 month old child recover from surgery like that in an institution unless you're really desperate. We kept him home after he recovered even though there were absolutely no community services for preschool children labeled retarded, and public schools were not admitting those who were deemed severely retarded.*

*So, we felt fortunate, isn't it awful that he had to have a big medical problem for us to feel fortunate, but we did. His medical problem brought the whole thing to a crux. And it obviously didn't hurt Bob a lot, thank heavens. To this day, I keep saying, "I wonder why he isn't mad at all of us for the life he lived." And my son, Rick, says, "Why do you keep saying that Mother? He knows you did your very best!" (Mary)*

## Choosing civic activism

Whatever the family's path, each of these five mothers reached their child's fifth birthday with a conviction that the quality of their family life depended on their ability to play an active role in their child's life at home, in the offices of professionals, in parent support groups, and in efforts to provide necessary services that recognized the rights and the needs of children with disabilities. They saw that professionals might be able to offer some help, but that they needed to develop their own point of view and retain their right to decide what made sense for their child. They realized from experience that they could count on the support of their husbands and children and the support of other parents both in their efforts to get through each day and in their work for change in their communities. They knew that, despite the operation of powerful prejudices, developmental disability did not compromise their child's inherent worth and their child's responsibility and right to make a contribution to the common good. They were beginning to realize that their children would be important guides to their own development.

These convictions have stood the tests of time. They have been the foundation for five careers of civic activism and for life situations for five people with developmental disabilities that exceed any expectation available to them when they were children.

*I can now look back at our life over the past forty some odd years and see what Bob has contributed in a positive way... How much wider and diverse my life has been because of my son... I said to my husband a long time ago, "We would just have known the people you work with, the people who live on the block, people we're related to, people we go to church with, period. And because of Bob, we know a whole lot more people in a whole lot of places, and it's marvelous." (Mary)*

## Essential lessons

Growing up with developmental disability teaches powerfully, if not always pleasantly. The voice that these civic activists bring to the boards they serve and the political forums they influence expresses the lessons of their experience. These lessons sometimes rub against the grain of understanding of legislators who feel that the job has been done for people with developmental disabilities, or administrators who think there are simple solutions to the problems of structuring support, or professionals who have worked hard to create far better ways to support people and families. However, the courage to speak the truth they know to people who have power in their children's lives lies at the foundation of their contribution as citizens.

### The critical importance of organized parent support

The chances for expanding and protecting access to the opportunities and supports that people with developmental disabilities and their families need depend on active parent organizations. These organizations draw their strength from the mutual support generated by people who recognize one another as sharing a common situation.

*What has really supported us over the years has been other parents. Knowing their experiences. Sharing our experiences with them. It was pretty difficult when he was little. One of the things I'm grateful for is that he was my fourth child. I mean, your self-esteem could suffer drastically if your first child was such a mystery. What in the world do I do with this child? If you'd had three others who were pretty smart and cute and everything's fine, you'd probably think, well, maybe it isn't me or maybe it isn't us. We went to the visually handicapped parent group first, but he obviously wasn't like those kids. And then we went to MARC, and he wasn't like any of those kids. So then a person who is still a friend of mine, her daughter is Brad's age, worked with some other parents of the "odd children out" and they formed an organization called "Help Educate Emotionally Disturbed" or HEED. We joined this group. All these kids were different, but they had commonalties, so we could tell there was something similar there. It's so funny. Parents of kids with autism seem to sense the commonalties even though there are big differences in how the kids function.*

*Everything has changed in forty years, but younger parents today don't know the history. They know what they have now — early, intervention, the right to education — what they don't realize is how much work it took us twenty-five years ago to begin to make these things a reality. We didn't have school for our sons and daughters. We were often even excluded from the special programs set up for kids with disabilities. What a lot of younger parents don't realize is that once their child legally becomes an adult, they'll no longer be able to take for granted an entitlement to services like they have with early intervention and public school. Many parents of children with autism don't even know that autism was not originally part of the federal definition of developmental disability. They just take it for granted. They don't know how much time and energy it took from parents to get autism included. (Fran)*

### Continuing difficulties in collaborating with professionals and assistants

Collaboration with the people who provide assistance can be an important source of energy and direction.

*When Bob was four, a woman who was on the faculty at Marquette worked for the ARC. She didn't have special education, or sociology or social worker credentials, but she was the home trainer that the ARC managed to recruit and we paid for her services. She was an outsider who appreciated him as much as the family did. She was the first one. She also introduced us to some other folks, and we formed a little neighborhood play group where the mothers took turns. That gave Bob his first socialization with other children.(Mary)*

*Mary Clare Carlson is the real reason that Bob now lives in an apartment. ... Mary Clare lives over the garage [of a house owned by Catholic Charities]. It wasn't a good setup for [the women] who were living in the house before Bob moved in. So Mary Clare said "Why don't you think about getting Bob in there?" And I said, "Oh Mary Clare, I love you. You can dream big. Impossible!" But we worked through it. It took a long time, and [even] when it was finally getting to the time to get started, it still seemed impossible, but I was willing to go with it. Try it. (Mary)*

Change has often required persistence, and agreements with professionals and administrators can be slippery.

*We'd walk out of a meeting and think, "This is going to work." And the next time we met we'd be back at square one. This went on for the entire summer. But, by golly, when school started, he was in that kindergarten class. (Sue)*

Rising consciousness of the ways services can contribute to negative attitudes can lead to conflict.

*Every aspect of his school life was this, you know, what they were doing, they were doing out of pity for the kids. "These poor, unfortunate kids." And when I went to work, I was visiting and ran into [a local affiliate of the organization] that had its "special day for special people", and thought it was just the most wonderful thing in the whole world. I just cringed.... And almost every name that people chose for the services was really awful as far as I was concerned. Of course, back then, we were still into naming group homes with names instead of just using an address. (Sue)*

Recognition of the fundamental importance of parent-professional collaboration shaped the invention of structures for working together.

*We wanted all the professionals in the room at the same time so that they had to hear what each other said, so parents weren't constantly being the messenger between one professional and another one. That was one thing we wanted. That's where the "M-team" idea originated. Every parent in that group had the same experience of one professional telling them one thing and another professional telling them something else, and not being able to get them to listen to one another. That was the basis for the M-team idea. (Fran)*

Advocating for new patterns of support calls for change that often generates resistance.

*I thought it was one of my better ideas for how to communicate without having written notes. [But the teacher's] response to my suggestion translated , "You asked for this integration. This is how it works." The subtext was, "I'll fix you for mucking up my life here and making it harder. My whole career has been based on this way of behaving. You whippersnappers come in here and think you are gonna change things. Well, I'll just show you." (Peg)*

Problems in collaboration become complex when both parents and service providers agree on the importance of adult autonomy but discover different understandings of the ways parents contribute to their son's and daughter's lives.

*They told me they didn't need to call me when there was a problem because I wasn't his guardian. . . The way staff see it is whether this person has come from the institution or nursing home or family home, "too much has been done for this person. They are very dependent. And WE ARE GONNA FIX THIS." And they think the way to do it is to cut the cord. To leave parents out, and that's just what they did in this situation. So, I just think the relationship between the paid staff and the family is something we could spend a lot more time on. There are so many things that I'm not through working out! (Peg)*

There are several possible explanations for problems in collaboration. These cannot be resolved easily because both families and service providers continue to be necessary to a person's life. So it is important to find new ways to understand and pursue relationships.

*. . .all of us who started off on this path of normalization didn't have adult children at the time and we didn't know that you're still connected to [your sons and daughters, disabled or not] all over the place whether it's money, or time, or worry, or happiness, or whatever. So, that element was there. But the underlying theme was, "You do this, and then your son or daughter will go off and have a job and live on his own and everything is just going to be roses." [That might explain] why we have families at loggerheads or in jealous relationships with staff and vice versa. (Peg)*

*When you produce a child, whose future is going to be less than the American Dream, you really get zapped by society in general. So, therefore, we can be very, very touchy. We are, indeed, glad when we encounter people working in the field who acknowledge the essential positive contributions of involved parents. For those of my generation whose kids grew up with no professionals out there to get hold of, who've worked so hard to get services going and get legislation to make possible all that, we feel like we've kinda gotten jobs for all these people who are now seemingly calling us overprotective, interfering individuals in our sons and daughter's lives... (Mary)*

*...one side should not put the other down. I hear parents who say, "You really don't understand because you've not been there." I've heard lots of parents say that to professionals. But that's their defense because the professionals are saying, "I went to college and I'm smarter than you. I know what's best." So parents have come up with their own defense... We need to rethink that whole concept. Parents and professionals both have something to give. And if we're going to survive with more people to take care of with fewer people doing the work and with less money at the same time we're spending more to put more people in prison, we're just going to have to do something differently. (Jayn)*

*The kids are all sitting around the counter as I'm making pancakes and I'm having at [my son], "Did you brush your teeth? Did you do this? Did you do that?". He says back to me, "This is my life. Leave me alone! My response was, "I'll never leave you alone. I'm your mother." (Peg)*

*We're seeing a change now. More and more people of my generation who moved away from our families are now seeing our kids coming back home with divorces, with grandkids. There are more people now who are raising grandkids. I hear it. Almost every time I talk to someone. Just last night I had a call from a friend whose daughter is in Eau Claire. Her husband left her. Her mom had to go up to her. You know, her kids are raised, but her daughter still needed her. And then her other daughter is having surgery and she's got to fly off to Washington to be with her. So you're still seeing that connection between parent and child even when that child has become an adult.*

*And then there's Amy's friend who fell in her apartment and broke an ankle and then where does she go? She has parents. She went back to live with them. And then she had a blood clot and ended up in the hospital, and then she was in a rehab center like a nursing home for like two weeks and then she was back at home. She needs to get back to her apartment. But you know you've got to have these transition places. This family had been on the waiting list for twelve years before their daughter got an apartment. She'd had a supported employment job ever since she'd graduated from high school, but she had been on the waiting list for a place to live. Now both parents are retired and they're in their late sixties. They wanted to make sure there was a transition so she could come home to visit. And thank goodness, now they've worked it out. They're seeing that it's not just move to an apartment and all is well. So, you still have to have that involvement. So all these things are showing us, I think, that the involvement of the family must continue. (Jayn)*



16

### Continuing uncertainties

Despite having achieved many victories and helping to build services that are the envy of people in many other places, the work of social change remains unfinished. Though much is spent on coordination, the system remains very complex.

*In some ways I have been Bob's case manager all of his life. Case in point: there have been two instances in recent years when it has been necessary to intervene, with the help of a county staff person, to reinstate Bob's full social security payment. (Mary)*

Changes in the political climate lead to concerns that what has been won could be lost, perhaps because parent's lose the strength that comes from being well organized.

*Could the rug be pulled out from under Bob's services so that he would have to settle for the likes of those things that he has been fortunate enough to move away from? (Mary)*

*We wonder [if] new parents know how quickly they could lose everything that has been won for them. I know. I went to Washington several times for the national organization to testify on the education law. … the fact that they were holding hearings, [raised the question] was this going to be the time that Congress decided that we didn't need this law… You could blink your eyes and it could all be gone. These attacks have gone on and on for years. (Sue)*

*… everyone is hung up on long-term care redesign. But part of redesign better be, "What kind of system are we going to design out there?" Putting all the money in one pot is only part of this. How in the hell are you going to… get the 8,000 people and families that are getting nothing some supports. We're not going to be able to give that 8,000 what we're currently giving the 23,000 [who are getting services] because the 23,000 are getting [a level of service] we can't afford [to give everyone waiting]. So we've got to rethink that whole thing. (Jayn)*

Families have made a variety of imaginative arrangements, but there is still no secure answer to the question that has haunted parents of people with developmental disabilities all over the world for at least two generations: "Who will keep my son or daughter safe after I die?"

*…every parent's [has an] all abiding concern about what will happen after both parents die. Supplementary trusts not withstanding, the wide, longitudinal, personal, case management function that very involved, not "overprotective", parents provide needs to be continued. Can an effective circle fill the bill or perhaps be the support that a brother, sister or close friend might need to feel able to step into that spot?*

*I've got to know while I'm still living that he can handle things without mom and dad around. From day one, I've sort of taken a backseat and tried not to always be running in to see how things are going. His brother and sister are close to him. His brother kids him a lot. His sister has four kids, so she's busy.… His brother picks Matt up and they have poker games. He involves Matt in his social life a lot. I even remember at one point I said, "Chris, I'm really*

*glad you're involved with Matthew, but I want you to know that I don't feel that you have to do it, that you have to be responsible for Matthew. He's got to learn to makes friends and do things, too." Chris said, "I don't do it because of that. He's fun to have around."*

*Matthew doesn't need a guardian, but he needs to have somebody who can manage his trust fund … I called Chris and asked him if he would manage the trust. He said, "Sure." (Sue)*

Circles of support and efforts to assist people with developmental disabilities to build a wider variety of friendships have made some difference to some people, but whether these relationships can be trusted over the long term remains doubtful.

*… as Bob's life is now, more community involvement in his social life would be the first step because it's so limited now. One of the things he likes is to do things with people who are not disabled.*

*Bob had a circle, but I must say that now he no longer has an active circle. I feel a constant need not to let his life disintegrate into [isolation or a life full or activities organized exclusively for people with developmental disabilities]. Sometimes it seems to me the only typical community activities that he has that are not designed for "his kind" are grocery shopping, church, ballgames, and eating out sometimes. Although he enjoys the friends that he has made in his segregated programs, he always tells us how much he likes to do things that aren't just for people with disabilities. (Mary)*

*We had always thought Eric was going to have [lasting] independent friendships, and it hasn't happened. In the past two or three years, there was a young man that the agency that supports Eric had linked him to. His name is Matt, and he taught Eric drumming. Eric paid him for the drumming lessons. And then Matt started doing things with Eric on his own. They would go out to movies, to clubs, or to listen to bands. He even came to some of the meetings we'd have with Eric. Matt did this on his own; he wasn't paid to do this. But of course, you know how young people are. They move and change. So that relationship just sort of slipped by the wayside.*

*So what is my nightmare? My first answer to that is that Eric will be lonely and slowly go downhill, and no one will notice it until he has crashed. And I have a lot of data that shows that happens. That he has to fall down before he's picked up. (Peg)*

*I see a flaw as far as Brad is concerned in the Circle of Friends concept, All of our closest friends have someone they are already taking care of. Everybody is so busy. I'm very active in my church, and I don't see those people or those I work on other causes with as having time to take on Brad. Some of them have husbands with Parkinson's; some of them have lost their husbands, or they are coping with a kid's divorce. Life is busy, and I don't see anybody having time to think about or even understand Brad. I don't predict anymore who will be there for Brad when I'm gone. People, even if they mean well, between being busy and not understanding him, I don't see them being there when I'm not.*

*One of his sisters is his stand-by guardian and another is going to be the trustee of a trust for him. They are both very smart. The trust is being set-up so it will pay their transportation to*

*come see him. But I am sure that if each of them gets here once a year that will be a lot. In the first place, they don't have a lot of vacation time. And they want to see their own children and grandchildren. They're going to be pulled three or four different ways.*

*I have a good friend on the Portal Foster board who was Brad's teacher for seven years. She has two children and she works full time, but she has said she will go to Brad's staffings if I ever need her, and then she'll call Betsy long distance and tell her what is going on. I call my friend the "guardian liaison". I would have a lot of confidence in her.*

*I have to hope that I live a long time! My mother lived to be 93, and I'm hoping I'll do the same. That would be nice for Brad. (Fran)*

After a generation's work, it seems to one of these activists that nothing less than an effort to shift our common culture, reconceive professional work, and transform the possibilities for use of public money will keep the journey of these civic activists moving along the path toward genuine opportunity and effective support for people with developmental disabilities.

*I still think it has got to be community. I think that's true for all people. I don't see it any different for Amy than I would for my own life or Bill's or our other two girls. In my book it's just all the same. Now some people use nursing homes for their family because they have their own lives and they've got their own jobs, other kids and stuff. But I think family has to come first. Right now I think we've got our jobs first or our own selves first and somehow we've got to start putting families first.*

*I know that many people with disabilities don't even have brothers and sisters that live in the same state. That's the same with other people, too. That may be fine but somewhere along the line we have to make sure that doesn't mean we all run away from each other. And I say that because I ran away. You know, my family is in Indiana and so is Bill's ...But we still have a very close tie to the family. ... They've all been very supportive and many of them have been up here during this past summer. You can live away, but that is no excuse to abandon.*

*We just can't have everybody living all over the country and society taking care of everybody. So I think family has got to get back into the picture, first and then the professionals.*

*But all along the line, the contribution of the families has not been valued. And that's where I see a big, big problem. When we calculate what a person needs in the community, we never calculate what the family's contribution is.*

*One of the things that the county has been having difficulty with is giving a parent the money to be a case manager. Why shouldn't a parent get it? A person I'm thinking of is a single Mom, and she needed the extra money. She needed to work herself. So, why couldn't she be that broker rather than paying someone else. Once she learned how to do all of this for her son, maybe she would do it for a second person. I mean, don't pile two or more on her right now, but let her grow into it.... Maybe [these parent case managers ] would only do this for ten or fifteen years... but to me there has been some duplication of effort when the parent has been doing most of the work, but we pay a separate case manager.*



19

*And this whole concept of people staying at home. We did a lot of pushing. I don't know how many parents have said to me that the system told them there was no help available unless their child was out of the home. [The system doesn't want ] to pay parents to be caregivers. But, we're going to have to [ask], "Why not?" … Parents have to have jobs, have to earn an income. I was able to quit to be at home with Amy, but Bill's job is so iffy. … So his being a caregiver and helping and getting paid has not been inappropriate in my book. He doesn't have any retirement at all, so he couldn't just up and retire. His employers are just tickled to death that he stays home two days or three days a week because they don't have the work for him. And by his doing this, they can keep him on part time. So the policy of requiring that the only way a person can get help is to move away from the family home has got to be rethought. I think we should try to support people no matter where they live.*

*There is a definite difference between what you do for a child with a disability and your other children. There is a definite difference between "parenting" and "caregiving". You can separate these things. And I don't have any qualm of saying these are the five things that you pay for under "care-giving" and you won't pay for "parenting" things.*

*So, you start with family, if there is family, and then you branch to paid service providers. Some of the professionals who work with folks 8 hrs a day will be willing to volunteer some time. I know that this is already going on. Then we have to figure out ways to get more people involved. There has to be some kind of role in here for volunteers, for friends, because society can't pay for all of this.… I think that as people have these circles, we have to have a way to have someone to … support them. Because I worked too, I know that when you work 8 hours your job is exhausting, and you have to have a life, too. I understand that. But that doesn't mean that you don't have eight hours a week that you can help somebody that you know needs something.*

*So maybe that's where we start. (Jayn)*

Whatever debate these bold proposals may stir-up, they respond to both current realities and a powerful vision of a future that offers people who need long term assistance and their families opportunities for a better life. Coming to terms with the issues that face these activists in the next decade calls for a growing number of parents to join in the work of civic activism.

## An ethic of active citizenship

Reflection on years of civic action to improve conditions for people with developmental disabilities reveals an ethic of active citizenship. Briefly stated, this ethic guides parents to invest in working cooperatively to discover ways to make things better for all people with disabilities. People have the right to freedom from prejudice, discrimination and abuse, and the responsibility to work to overcome these evils. Any rights or privileges people may have regarding services or community opportunities entail a responsibility to contribute in ways that make the system and the community stronger.

This ethic can be further defined in terms of principles that these citizen activists have tried to live out in their relationships with other families and in relationship to the service system:

*Regarding your family*

- Have high expectations for your child and your family and expect publicly funded services to offer real and relevant help. But realize that even the best service providers and system managers need you to invest in identifying and solving problems with them. Don't tolerate poor performance, or denial of real problems, but don't expect perfection.
- People with developmental disabilities and their families deserve a fair share of public funds. But funds are scarce and many other people with the same eligibility you have are in need. Don't take more than you really have to have. To identify your own family's need for services, consider what you can do for yourself with the social and material resources available to your family and extended family. Don't ask the service system to provide or pay for what you and your family can manage on your own, even if it means dealing with tough family questions.
- What your family needs may not have been invented yet. Hold system managers and service providers accountable to work with you to figure out how to make what is necessary possible, but don't expect them to work magic or get it right without your contribution.
- Find ways to reach out to other families and invest energy in strengthening and extending the network of family members and the organizations that support that network. Go the extra mile to discover common ground with other parents. You may discover differences of values and vision that you cannot bridge, but don't give up easily.

*Regarding the service system*

- When a worthwhile program excludes you or doesn't work for you, get involved and work to improve the program. Others may succeed in rejecting your efforts to make a positive difference, but it is your responsibility to try, not just for your own sake, but for everyone involved. Pull out of a poor program if necessary, but not before making an effort to help.
- Be alert to discover who is most at risk under current policies and work to improve

their situation. Are people being excluded because they are too difficult to support? Are people who only need a little help being denied it because they have become ineligible? Is the work of providing technical and demanding care falling unfairly on parents because the system is trying to limit expenditures? What effect does race, income, and immigration status have on the quality of support people with disabilities receive? Make these vulnerable people's situation your concern both because you accept your share of responsibility for the effectiveness of the whole system and because what happens to more vulnerable people today may be a rehearsal for what the system may bring to you next.

- The system and its programs need effective governance. Contribute time to board and committee work not just to advance your own agenda but to broaden your understanding and make a contribution to improving others' situations.
- The system is partly a creature of local, state, and federal politics. Expect to stay politically active and encourage and support others to be active as well. The political process will generate frequent threats and occasional opportunities. Only people who are willing to be involved over time will develop the skills, information, credibility, and contacts necessary to have influence. To be cynical without being involved isn't helpful.

These principles describe an ethic of commitment to change unjust conditions through responsible connectedness.

*We have not succeeded on either the federal or the state level at creating the same entitlement to community services that medicaid eligible people have to go to a nursing home or an institution. As medicaid keeps getting bigger than anything in the state budget except prisons, we can predict some scary things. Medicaid rationing will increase, and it may well be done by "care managers" who have no direct connection with or knowledge of the families they are saying "no" to. Community services budgets will get squeezed, and it will be harder and harder to respond to crises for people with severe disabilities without sending people to nursing homes. The nursing homes won't want to fill up with the most costly people because they won't be able to make as much profit by averaging their costs. That means they will push to lower the standard of care. They'll probably argue that this will "get government off people's backs" or "cut unnecessary red tape". As the standard lowers, more people with developmental disabilities will either get so debilitated that all the nursing home will have to do is provide physical care, or they will die. Either way, the nursing home will look like the cost effective option and community services will focus on people with moderate needs. The whole system works now; but it's pretty vulnerable.*

## Unfinished business and the troubling growth of a sense of "entitlement"

A generation of sustained and creative citizenship action at the county, state, and national levels has influenced many changes in the opportunities available to people with developmental disabilities and their families. There is a clear, if occasionally contested, right to public education; there are greater provisions for family support; there are more and more effective means of individualizing support for employment and home life; there is a continuing revolution in assistive technologies. Medicaid, Medicare and SSI benefits have been established. Public funds for services to people with developmental disabilities have steadily increased. The Americans with Disabilities Act and a variety of other laws make some forms of discrimination illegal.

### Unfinished business

Despite these victories, much unfinished business remains. Growing waiting lists for residential supports for people who have grown up and grown older with their families are one sign of this unfinished business. Increasing numbers of people with no alternative to nursing home placement suffer the realities the waiting list symbolizes. Growing numbers of denials and denied appeals for medically necessary services are another. Some of these denials deprive people of services that will prevent further difficulties, others deny needed help on the grounds that the person's disability persists, others reduce the basic supports a family needs to stay together. All make life more uncertain and more complicated. Families of children with complex medical needs, squeezed by the gap between high-cost high-tech medical interventions which make survival possible and unresponsive and diminishing support services that expect more and more from mothers who are already investing much of their energy in the work of care, suffer the realities of these cost cutting exercises. So do the people who face transfer from a community residential service to a nursing home because they have acquired additional disabilities that take them beyond contracted levels of service.

Despite more than thirty years of advocacy, the system remains biased toward institutions and former institution residents. Many people who were institutionalized now live far better lives with much more effective support, but from the point of view of many parents who kept their families together into adulthood (sometimes into old age), most of the systems' money seems to recycle around institutions and their former residents.

*There are two things we haven't yet succeeded in doing. 1) We haven't been able to reach consensus on standards for community services, so we can't really make sure that people get good quality when there are arguments with providers; and 2) we haven't done the research to prove the claims we made when we told legislators that if they spent a dollar on this program we would save two dollars later, so our case is weaker when we come back for the next dollar. (Jayn)*

Experience shows that what has been won with great effort risks being undone with the stroke of a pen. As services to people with developmental disabilities have become more and more complex and tightly linked to medical assistance funding and other benefits affected by changing attitudes toward poor people, the quality of support can be as powerfully influenced by administrative action as by legislative decisions. The trend to managed care is only one of the most visible threats to the development of an adequate resource base for services to people with developmental disabilities.

Finally, a growing segment of the service system effectively supports many people to live safe and interesting lives. These efforts need sustained investment from family members in order to keep improving. As counties with a history of progressive practice redesign their services to explore self-determination as a way to improve quality and contain the growth of costs, there is a vital role for parents in assuring that people with significant disabilities are adequately represented and effectively served.

### Entitlement, a troubling new mood

The gravity of this unfinished business makes citizenship action with and on behalf of people with developmental disabilities as important now as it ever was when there were few programs and policy mostly concerned institutions and their waiting lists. The urgency of the need for parents to exercise citizenship makes the emergence of a sense of entitlement among parents particularly troubling.

Entitlement is like a mood that forms the background to people's relationship to the service system. People take entitlement for granted and feel righteously angry and resentful when people question it. Parents who display this sense of entitlement act as if they believed that...

...they have a moral, if not a legal, right to whatever services they decide are necessary; awareness of lack of appropriated funds or capacity to deliver the desired service leads to blaming and even threatening service people rather than stimulating effort to influence the political process or negotiate a way to contribute to service development

...no responsibility to invest time in building up the network of families or in civic action to strengthen local capacity to support people with developmental disabilities corresponds to their sense of a right to receive services

...the presence of disability alone defines the level of service they can reasonably demand; the suggestion that families have a responsibility to mobilize and contribute their own resources feels like a violation of fundamental rights

...it is important to know and work the system to maximize the services and benefits available to one's own family while remaining vigilant to notice other families who get a greater share of services; this competitive sense of fairness makes people angrily opposed when policies that attempt a flexible match of available money and demonstrated need appear to leave others better off than they are. It can even lead people to feel and express resentment about what they perceive as reverse discrimination on the basis of race or income

...it is reasonable to treat service people as if they were servants whose task is to deliver services to family specifications with minimal inconvenience to family members; invitations to collaborate in figuring out difficult problems are dismissed as an affront to the consumer's dignity

The mood of entitlement encourages parents to view disability as their private matter and a public responsibility. Community services should replace the institution in the sense that parents should expect services sufficient to remove most of their concerns about disability and most of the work of caring without the necessity of investing in civic and personal action. Community services should improve upon the institution in the sense that the individual services each person receives should be under family control and be free of the stigma that attached to institutionalizing a child and the necessity of investing in the system that provides services. This sense of things seems to rest on a confusion between legislative victories and established rights. For example, winning a growing investment of public funds in housing does not constitute a right to housing. It simply establishes a limited capacity that the service system can use.

Even when a legal right has been established, as some rights to public education and due process have been established for children in special education, the mood of entitlement can lead people to overestimate the scope of these rights and underestimate the continuing difficulties of creating an educational experience that actually makes sense for each child.

The mood of entitlement shapes a family's relationships with neighbors and other community members. It can lead families to act in ways that discourage people who could help out from offering support because they fear trespassing on what families have taught them to see as the work of professionals and paid service workers.

Some parents might say that the past generation of activist parents worked for and won the rights that allow them to expect disability to make a minimal difference in their family's everyday work of caring and minimal demand on them for active citizenship. When the current system functions below these expectations, the problem lies in the system's failure to respect family rights and the remedy lies in compelling enforcement of these rights.

People who say that these rights have been or could be finally won don't live in the same Wisconsin as experienced citizen activists do. In the activist's Wisconsin, good, even wonderful, things are possible for people with developmental disabilities, but these good things are...

...the result of sustained collaborative relationships

...vulnerable and almost certain to encounter problems that call for renewed investment, especially when a person's needs or family circumstances change

...available to far too few people

...*not* guaranteed by enforceable rights to community services



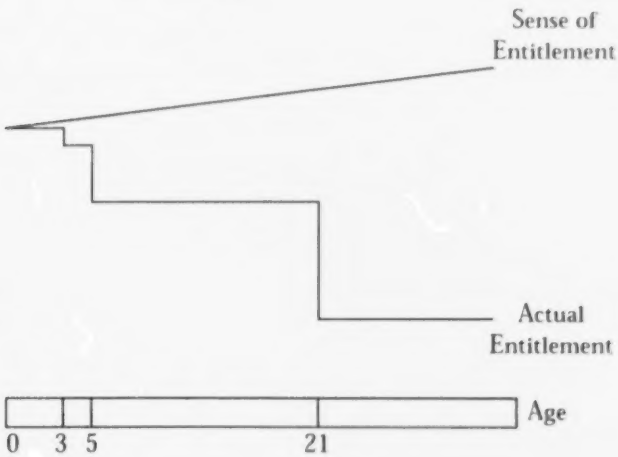
25

### The mood of acceptance

While discussing the difficulties with a growing sense of entitlement, it's important to remember that many parents continue to do the work of caring for their sons and daughters from the position of making the best of their private troubles. They may appreciate whatever the service system can do, but they do not see their family's future as anyone's concern but their own. These parents live so far outside the mood of entitlement that they have no confidence in seeking resources for the future. This results in people being thrown into the service system when parental support breaks down, which too often leads to placement in whatever congregate facility has an affordable vacancy. People in this position today need the same things they needed a generation ago: the encouragement and information necessary to mobilize available resources. The best source of this support remains a strong family network which holds both high expectations of publicly funded supports and high expectations of family members as active citizens.

These families are unlikely to get the support they need to become personally and politically mobilized if a significant proportion of the family members with the resources for activism spend their energy on trying to make the world conform to their sense of entitlement.

### Living in the entitlement gap




The diagram suggests the gap between some parents' sense of entitlement and what existing law allows. Actual entitlement decreases with age, as suggested by the stair-step (or cliff) shape of the "Actual Entitlement" line. Eligible infants are entitled to a variety of defined family directed supports, as long as the state opts to participate in offering the program. Adults have the right to contest legally defined discrimination in public accommodation, and are entitled to certain benefits, usually SSI and Medicaid, as long as they maintain eligibility. But the definition of benefits and conditions of eligibility change at legislative and administrative discretion, as the growing number of denials of

medical assistance funded services for school aged people shows. For some parents, the "Sense of Entitlement" remains high even as actual entitlements drop away. Parents express this sense of entitlement when, for example, they learn of the availability of housing assistance for some people with disabilities, and then demand that the service system honor their child's "right to a home", and then act resentful when informed that, while no right to home ownership attaches to developmental disability, willingness to invest time, energy, and money in collaborative work has good odds of developing a way to finance suitable housing.

It makes sense to continue the political work necessary to assure access to sufficient community services for every eligible person. This work takes courage, persistence, and a talent for scheming. The political climate more often produces plans that will take away the share already allocated to people with developmental disabilities or schemes to stretch federal medical assistance funds to patch another gap than to straightforwardly expand their share of public funds. But even success in achieving sufficient funding and policies that promote family and individual control of services can't meet the demands that generate the entitlement gap.

Living in the gap between sensed entitlement and actual entitlement (the grey area on the diagram) creates the same kinds of problems for families as any other long term state of denial. Parents don't feel the importance of reaching out and building up the kind of relationships that will bring them the kind of support and information that would lead to better decisions. They assume that they can command what they require. They don't make the sort of longer term investments that will multiply their future options because they don't feel the necessity of planning. They assume that when something is needed, it will be there. They don't learn the problem solving and negotiation skills necessary to make complex support arrangements work as well as they can. They are seduced into simple answers and don't take the time to figure out the complex realities that face people with developmental disabilities. Problems are denials of rights which can be overcome with assertiveness or by reaching for a legal hammer.

The unreality of these expectations simply tightens their grip. Opportunities to join in discussing issues or taking action to improve conditions are dismissed without hearing or rejected as irrelevant or backward. What happens to others doesn't matter; it won't happen to us because we know our rights. Instead of critical appraisal of possible opportunities, thoughtless applause greets promises of "parent empowerment" or "commitment to consumer satisfaction" or "self-determination". Instead of a careful eye on the quality of services, compromises to decent living conditions get celebrated as the best possible services. Others carry the blame when expectations of entitlement go unmet. Resentment uncurbed by social conscience can send people down a scale of blaming that risks a slide into racism: from ignorant or oppressive professionals, to poor families who squander public money, to in-comers from other states, to immigrants from other nations who take what they do not deserve.



27

If the number of parents who live in the entitlement gap grows too large, the whole community loses. People who take entitlement for granted seldom spend time doing the necessary work of boards, planning groups, parent support groups, and political committees; and so staff and lobbyists define the compromises that shape the system's growth. Active involvement in the parent network may not outlast the time it takes for a family to get what it needs; and so the network withers from lack of sustained involvement. When belief in entitlement to whatever appears necessary seems like all the information anyone needs, parents have little reason to study and develop positions on complicated questions; and so the system becomes more distant and more complex. When denial of rights passes for the real reason that anything fails to work out, parents who invest time and talent in the gradual business of improving the structures people count on for support may be defined as enemies; and so potentially fruitful disagreements among people with a common interest get polarized into camps that talk about each other rather than to each other.

Living in the entitlement gap leaves little room to develop the habits of citizenship and civility. Denial of the gap makes many topics undiscussible and puts entitlement first and last on any agenda. Important relationships go untended and the work of guidance for individual supports and governance for the system and its components defaults to staff.



28

## The path to active citizenship

The point is not to complain about the corrosive effects of a growing sense of entitlement; the point is to discover ways to invite more people to follow their own path of active citizenship. A better understanding of the differences a generation has made offers a place to begin this search. The shape and difficulties of citizenship has changed because of large scale changes as well as changes in the service system.

### Social changes affect the conditions for volunteer action

*Then*

In order to allow the choice to keep her family together and become civically active, the activist mothers of the past generation developed…

*To put in the time to do what we did voluntarily, we had to be families with one income and two cars.*

…the ability to meet their children's needs for care in a way that left time and energy for active citizenship

…support from their husband and family

…either sufficient family income to subsidize volunteer time or a job that allowed time for both family responsibilities and citizenship

Though there were conflicts, compromises, and setbacks, the times favored an expanded role for the federal government in promoting civil rights and funding services for people with disabilities. Many activist mothers discovered unexpected abilities in themselves and a welcome sense of fulfillment in jumping into new and difficult situations and discovering that their involvement made a real difference.

*Now*

The **role of women** has changed. Today, it is harder to make the time for person to person support and harder to make the time for citizenship action. Many more women work, and, though sexism continues to distort the labor market, a growing proportion work not only for wages but for the fulfillment of pursuing a career. More women practice professions or pursue entrepreneurial activities that demand high commitment, more employers expect workers to make a personal investment in their jobs, and mothers on public assistance face demands that they develop their skills and succeed in employment. A small but growing number of women have moved from political background work into elected and appointed office. The number of mothers of children with disabilities who work in human service and advocacy agencies has grown significantly. The number of single mothers has increased and the number of two-parent families that manage on a single income has decreased. Mothers with disabled children have more services to help and more responsibility to coordinate multiple benefits, programs, plans, and sometimes appeals. Many mothers hunt for time for civic action in complex household schedules that juggle the demands of home, work, and support for their children's own schedules. A growing recognition of fathers' shared responsibility for doing the work of caring makes our repeated references to mothers sound restrictive, even if many fathers in fact continue to remain in the background of their children's lives.

*Some of us needed the income from work, so we found jobs that paid us to keep on doing what needed doing.*



29

The **political climate** has changed. As important as it is to expand public funding to meet the commitments implied by eligibility criteria and waiting lists, many people believe that aligning the political will to do it represents a near impossible dream. A willingness to bet the well-being of people with developmental disabilities on simple, managerial solutions haunts the highest levels of deliberations about how to provide long term support and repeatedly threatens to overwhelm the efforts of more thoughtful and creative reformers. Human service work and public service hold less value than directly contributing to the market does. The virtual tax payer who is assumed to demand impossibly tight control of funds carries more weight in many discussions than real taxpayers with useful ideas for spending public dollars on the common good do. State operated institutions have survived repeated closure attempts, despite using nearly a quarter of the budget to serve less than ten percent of the people now in the system. Squeezing people's benefits exemplifies enlightened public administration.

**Demographics** have changed. The state as a whole and many of its communities are home to people of diverse races and unfamiliar ethnic backgrounds. The number of elders continues to grow and with them the number of people requiring long term support.

The **tone of public discussion** has changed. The media amplify sentiments that only a few years ago would have seemed too mean spirited or too prejudiced to speak aloud. People cluster with others who reinforce their views rather than finding ways to seek common ground with those who have staked out a different position. The uncertainties that many people feel due to **economic changes** are easily channeled into resentment of some "them" who can be held to blame. Some people organize to respond to race and ethnic prejudice by amplifying their differences from others. In this climate, talk of citizenship, community, shared effort, and seeking common ground by dealing thoughtfully with complex public issues seems naive if not downright silly.

### System changes challenge citizen control

*Then*

For these mothers, the choice of active citizenship didn't come all at once, but in steps that matched the growth of the system. As they decided that their families' chances were better if they were not isolated and dependent on local professionals for information, they sought and found others who shared some of their experiences and concerns. Some chose mentors among older parents. Finding other mothers in similar circumstances led to the exchange of practical help in such forms as bartered child care and traded rides. It also led to shared information, the invention of new ideas, and mutual encouragement to take action in support of one another's projects.

There were few community services, and most were parent founded and controlled and combined service provision, personal support, and advocacy. Some children's disabilities disqualified them from participation, but for many families there was one place to go for whatever the locality had to offer. Laws and funding mechanisms were minimal, benefits

were few, public administrative structures were rudimentary, and programs were simple and aimed at meeting basic needs for education and occupation. Most decisions were made locally. Mothers who wanted to be active found many opportunities open to them as organizational officers, committee members, public board members, and advisers to politicians with a new found interest in disability policy.

It was a breakthrough when activists whose children had different disabilities met and learned from one another through forums like the Madison Special Education Advisory Committee and went on to form working relationships across disabilities. These relationships stimulated a debate that led parent advocates to work together to improve conditions for all children with disabilities, regardless of label. This local decision was mirrored on the national scene by the coining of a new wider category that included mental retardation, cerebral palsy, epilepsy, and later autism under a single label: developmental disability.

The process of involvement in active citizenship was not so much like a straight line as a sort of spiral. *Not*, first get your child's needs taken care of and then get involved in helping others, *but* improve your ability to meet your child's needs both now and for the future by the ways you get involved with others. *Not*, first get your own act together and then donate the energy that is left over to citizenship, *but* grow stronger by becoming a more active citizen. As one involvement led to the next, contacts, relationships, knowledge, skills, and confidence expanded step by step. Like Paul Bunyan, who could lift his full grown blue ox because he built his strength by lifting it each day of its life, this generation of citizen activists has remained able to understand much of the system they helped to build, even though they have not always been able to make it work smoothly to meet their own changing family needs.

*Now*

*As the system gets more complicated to use, the risk of stratification goes up: those with the skills to get resources will get more, families with less will get even less.*

There is **more to keep up with**. Parents face a great deal of information and many different and often conflicting professional opinions about what is best for their child with a developmental disability. There are multiple therapies and programs to choose among and a complex and changing set of benefits to apply for and maintain. There is an array of advocacy and support groups. Good quality family support programs offer families the opportunity to direct the expenditure of small but helpful amounts of money and to recruit, train, and supervise respite workers and assistants. Many school programs offer some choices about schedule and curriculum. This flexibility comes at a cost in coordinating time and in responsibility for decision making. The more common expectation that parents should support their children with disabilities in typical social, cultural, and recreational activities is hopeful but demanding, especially when accommodations must be negotiated and renegotiated. While many parents find and appreciate the support of mentors, a growing number seem to feel that their experience differs too much from that of older parents to make a mentoring relationship meaningful. It is easy for parents to feel that the volume of potentially relevant information and significant decisions that must be processed pushes them into disability life over their heads.

The **system is more complex and more distant**. The US federal medicaid program has arguably been the most powerful force shaping community services for people with developmental disabilities over the past generation. From its earliest days, Medicaid has been an instrument to increase expenditure on nursing homes and institutions for people with developmental disabilities, with the rationale that increased funding and more stringent regulations will remedy abuses and produce good quality institutionalization. The flow of medicaid funds made nursing homes profitable and greatly increased expenditures on facilities and staff in state institutions, strengthening the political influence of nursing home operators and institution unions. Like most other states, Wisconsin has negotiated a series of different waiver agreements to permit the carefully regulated use of medicaid funds on services for different target groups. The proportion of state community aid funds in county budgets has declined relative to the amount of medicaid money in county budgets. Medicaid money brings strings, reduces local control and makes the local system more difficult to understand. The quality of services comes to rely more on the administrative maneuvering and negotiating skills of county and state managers and less on the quality of governance by local citizens.

*Here is an example of how medicaid has changed the system. Some years ago we had a small, effective program funded with state general funds to provide assistance to some people with physical disabilities so they could stay at home and keep out of nursing homes. Then along came the idea that if we made this into a medicaid funded program, we could increase the amount of money available and increase both the number of people served and the variety of different disabilities served. The results show the trade off. On the positive side, more people get help that can be individualized. On the negative side, the program moved from local control to a more medically oriented kind of management with guidelines and rules from the state and federal level. There is more overhead and the descriptions for simple kinds of help necessary to get through the day got bastardized to meet medical sounding definitions and got harder for legislators and administrators to understand. And the politics got strange. The program was planned to expand both numbers and money from a low baseline. But all of a sudden some politicians started saying the program was out of control; that it had grown by 600%. It became an example of why the system needs for-profit care management and limits on individual expenditures. People with a political axe to grind accused people who were just using some available help to get by and get on with their lives as abusing the system and being too costly to live in the community. It's a pretty big downside to getting more people some of what they need, but its the kind of price we've had to pay. (Jayn)*

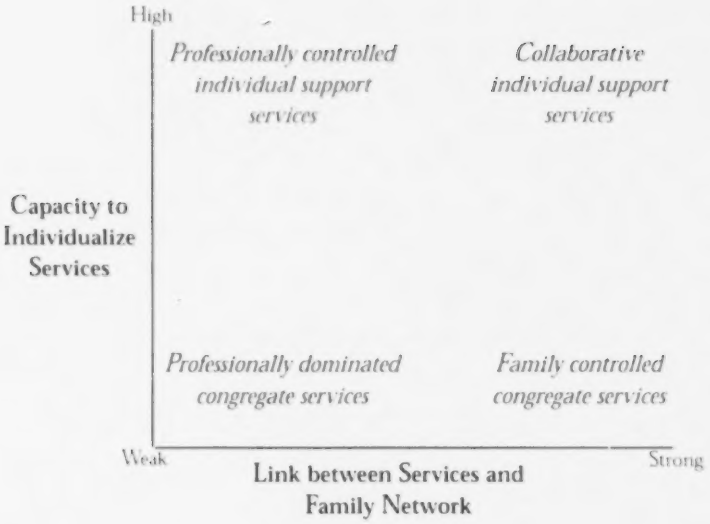
Local service systems developed under 51 Boards as local citizens and elected officials with a specific mission to serve people with developmental disabilities planned, made decisions, evaluated and grew the system. Some counties did better than others at meeting these obligations, but the responsibility belonged to local people. Parents who wanted to improve things for people with developmental disabilities could get involved. A trend to streamline county organization charts made use of legislative authorization to

consolidate functions and now the developmental disabilities is one of a number of sub-programs in County Human Service Departments.

Many services for people with developmental disabilities have been swept up into a new public policy category that includes services to elders and people with physical disabilities: long term support. Elders account for most of the demand for long term support because their numbers are so big. As the state plans to redesign its long term care system to get medicaid expenditures under control, the agenda for people with developmental disabilities could easily get lost, especially because some advocates for other groups believe that services to people with developmental disabilities are excessively costly. In such a big, complicated program, it's hard for citizens to understand all the issues, define positions that make sense both for people with developmental disabilities and for people with somewhat different needs, and make their voices heard.

*The potential effects of rationing on people with developmental disabilities are frightening. Think about families with children who need intensive nursing care. These children survived because of advanced medical care. They went home with their families because living at home is cheaper, even with very intensive paid support. It's also much better for the kids. But these families are getting squeezed. Somehow our system doesn't value the support services families need to keep a kid alive and thriving as highly as it values the doctoring that allowed them to survive. The squeeze comes as supports are pulled back and services are denied. To some of these mothers, it seems like the system is telling them, "You have to work eight hours. We'll let you sleep a few hours. The rest of the time you provide high-tech nursing to your kid." Families are surviving this, but over the long run it seems likely that more kids will die and more kids will end up in nursing homes. When are these parents supposed to find time to advocate? The system seems to be doing its best to make sure they are too tired and stressed to make their voices heard.*

The **parent network weakens** because fewer parents invest time in building the network and the organizations that support it. Some people think that when parent organizations spun-off the services they operated in order to focus on advocacy, they gave away not only much of their financial base but also a clear local identity for the parent network. Others point out that parent organizations that have continued to operate services can have significant difficulty involving the parents of younger people with developmental disabilities and that the services offered by long established parent run organizations tend to be congregate programs. Whatever the cause of a weakening network may be, and whatever the cure, the challenge for local citizens is clear. The diagram describes four different possibilities. The least desirable situation is unfortunately common: a weak parent network and a limited local capacity to individualize service to meet different needs and preferences result in professionally dominated services that process people in groups. The challenge is to strengthen the parent network and link its energy to local services in such a way that there is real collaboration in developing individual supports.




One barrier to the kind of collaboration that experience shows necessary may come from an unexpected direction. As more and more people with developmental disabilities find their own voices, both individually and through groups like People First, some service providers have come to question the legitimacy of the role parents have to play in advocacy and governance, even for people who have guardians. Indeed, some people are questioning not just the numbers of people with developmental disabilities who have guardians and the extent of individual guardianships, but the idea of guardianship itself. Many others seem to finesse the question when they speak about the move toward self-determination by referring to "the person with a disability and others the person chooses." Given that some people with developmental disabilities have very limited capacity to communicate their preferences in complex matters, strong and thoughtful parent voices need to be involved in deliberations about self-determination.

*I'm concerned about the effects of the proposal for self-determination on people who have guardians. So I did a preliminary survey of several agencies that serve about 300 people among them. Staff believe that only about 50% of the people in vocational and day services who have guardians currently have an active person from outside involved in their lives. For people in residential services, the percentage drops to less than 25%. This means that the new service brokers will become very powerful in the lives of the most vulnerable people. (Fran)*

## Lessons

- Parents with very different visions for their own sons and daughters can find common ground and work together for important changes. Take time to listen and question each other to discover what you can work on.
- Victories can have unexpected consequences. Some will be positive, some will be negative. This is especially true when we win only a part of what we need. Keep your eye on how things work out over time.
- Broader coalitions increase political clout, but once legislation is passed and appropriations are made, there will be lots of questions to settle about how the benefits are divided. Don't feel bad about having to protect a fair share for people with developmental disabilities.
- Insiders in the system can and will be a lot of help when you discover common issues with them. However, don't expect them to stand up in public and take responsibility for things that don't match their agency's agenda.
- What took years to gain can be lost at the stroke of a pen. Even when a change has been implemented it can be lost. Administrative changes in the way laws and rules are interpreted can be as big a problem as changes in laws or regulations.
- Learn to ask for help and to relinquish control when necessary in the interest of attaining what seems to be important (this one has to be constantly relearned).
- Families need to be involved in finding solutions to problems not just to identifying problems.

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35